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Title: YouTube as a source of information for patients considering surgery for ulcerative colitis

Short title: (max 40 characters with spaces): YouTube surgery for Ulcerative Colitis

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Paper category: Gastrointestinal

Abstract

Background: With the range of health information online, assessing the resources that patients access may improve the content of pre-operative information. Our aim was to assess the content of the most viewed videos on YouTube related to surgery for ulcerative colitis.

Methods: YouTube™ was searched for videos containing information on surgery for ulcerative colitis. The 50 most viewed videos were identified and user interaction analysed. Upload source was classified as patient, individual healthcare professional or hospital/professional association. Video content was categorised using an inductive thematic analysis on a purposive sample list of videos. The overarching theme of each video was classified once data saturation was achieved.

Results: Thirty videos were uploaded by patients, 15 by hospitals and 5 by healthcare professionals. Seventeen videos (34%) discussed life after surgery. Sixteen of these were uploaded by patients who had previously undergone surgery for ulcerative colitis. No videos of this theme were uploaded by healthcare professionals. Ten videos (20%) described a number of different operations. Other themes identified were alternative health therapies (12%), colonoscopy (12%), life with ulcerative colitis (8%), miscellaneous (8%) and education for healthcare professionals (6%). Patient uploaded videos had significantly more comments ($p=0.0079$), with 28% of comments on patient videos being users requesting further information.

Conclusion: Understanding the sequelae of surgery is most important to pre-operative patients. There are a lack of professional videos addressing this topic on YouTube.

Healthcare professionals must participate in the production of videos and adapt pre-operative consultations to address common pre-operative concerns.

Keywords:

Elective surgery

Electronic resources

Ulcerative colitis

Shared decision making

Introduction

In the first ten years following a diagnosis of ulcerative colitis (UC), 1 in 10 patients will require a colectomy, with 20-30% of patients requiring surgery in the long term ^{1, 2}. Surgery may be performed acutely for severe active disease, perforation or excessive bleeding. More commonly, surgery is performed electively for disease refractory to medical treatment ^{3, 4}.

The decision to opt for surgery is difficult both for the individual facing the choice and clinicians providing the advice. This is particularly the case when considering elective surgery; patients may not be acutely ill and the option of further medical treatment exists. A surgical option can offer an improved quality of life and reduced drug side effects but may itself also be associated with significant complications ⁵. Current guidance emphasises the importance of information about treatment options for people considering surgery, including specific information about what to expect in the short and long term after surgery ⁶. However, it was acknowledged that there was inadequate guidance on the specific content of such information.

It is estimated that 50% of patients with inflammatory bowel disease use the internet for information relating to their condition ⁷. Patients may seek health information from the internet at least as frequently as from their gastroenterologist (38% vs 36% respectively) ⁸. A key principle in the consent process is to give the patient time to consider their decision by conducting further research – both with extra reading and searching the internet ⁹. With this, patients and their carers will look to the internet for information to support their decision.

YouTube™ (www.youtube.com) is a video hosting website. Strings of free text can be searched in a natural language format, with a list of videos produced in order of perceived relevance based on keyword density in the title of the video, and access by other users. Content is free to access, widely accessible in geographic terms, and is not peer reviewed. Site features include the ability to 'like' or 'dislike' a video, provide written comments on it, or search for specific videos on the site. Users that are unregistered can watch videos however they cannot upload their own material. Registered users are capable of uploading an unlimited number of videos that must respect certain 'guidelines' such as no graphic content or copyrighted materials ¹⁰. The only limitation across the website is where content is deemed inappropriate for all ages, users must be registered and over the age of 18 years old to watch the video ¹¹.

Currently there are no studies assessing YouTube videos about surgery for ulcerative colitis. We believe that assessing commonly viewed videos on YouTube could provide a description of what patients access outside the clinical encounter. Our research question was: what is the content of the most commonly viewed videos on YouTube when directly searching for information about surgery and ulcerative colitis?

The aim of this study was to assess the thematic content of the most viewed videos on YouTube discussing ulcerative colitis and surgery. A secondary aim was to ascertain to user response to these videos.

Method

A YouTube search was conducted on the 3rd June 2016 using the search term 'ulcerative colitis and surgery'. This search term was established from concurrent qualitative interviews with patients who had surgery for ulcerative colitis, and was confirmed as the most popular

search term that patients would use, or have used, by patients involved in a public-patient involvement day for related trials for inflammatory bowel disease. The use of additional search terms was deemed as unnecessary as preliminary searches illustrated large content overlap between different search terms e.g. 'Ulcerative Colitis colectomy'.

Videos were subsequently filtered according to the number of views. In a systematic approach, the top 50 videos were independently analysed by two medical student researchers, with training in qualitative methodologies (D.B. and J.M.). The first 50 videos were set as the cut-off for a number of reasons. Firstly, this methodology is a hybrid of a citation analysis and a thematic analysis. We chose 50 videos as, during preliminary searches, we noted videos appearing after the 50th video had a lower view count. We also felt that 50 videos were more than adequate to achieve a robust thematic analysis without coding an unnecessary volume of data. Lastly, previous work using qualitative methods to assess YouTube uses similar sample sizes to that used in our analysis ^{12, 13}.

Video demographics including number of views, likes and dislikes were recorded. Any disagreements over the number of views, like or dislikes, or discrepancies in categorisation were solved by an independent reviewer who is a specialist in general surgery (M.L.).

The upload source of each video was classified as patient, individual healthcare professional (HCP) or hospital/professional association (PA) based on the 'about' section of their YouTube profile. A patient uploader was someone with UC or IBD. Hospital/professional association uploaders were specific hospitals/clinics or medical societies. Individual HCP uploaders were professionals acting individually to upload videos. Some PA videos talked to HCPs as part of their video however they were classified as PA if they were uploaded by specific hospitals or clinics.

The top 10 comments on each video were analysed and were classified as further information requests, comment praising or critiquing the video, user sharing their own personal experience or irrelevant comment. Comments were classified as irrelevant if they were unable to be understood or they were not related UC and surgery. Some videos had comments disabled and this was noted for later analysis.

Categorisation of video content

A thematic construct was developed using purposive sampling of 14/50 of the videos to represent the upload sources with varied characteristics (male/female, age, pre-op/post-op). This method facilitates identification of themes until saturation is achieved and other content can then be fitted into this framework. Videos from the sample were transcribed verbatim and analysed using an inductive thematic analysis model on the QSR NVivo 11 Computer-Assisted Qualitative Data Analysis Software (QSR International, Melbourne) ¹⁴. Codes produced from the analysis were used to generate emergent sub-themes in each video. Using these themes, we categorised the overarching theme of each video. Emergent themes and video transcripts were discussed collaboratively by three reviewers (D.B, M.L and G.J) to ensure consensus was achieved.

Data saturation was assessed after the 14th video – with transcription continuing until no new themes emerged. The remaining videos that were not transcribed were then assessed and assigned into one of the overarching themes based on the main content of the video. As data saturation was reached, the remaining videos were expected to fit into one of the overarching themes produced from our thematic analysis.

This method of content categorisation was chosen to ensure video content was established using transparent methods. It also ensures video content categorisation was not reviewer-

specific as analysis of transcripts allowed detailed exploration of emergent themes of each video, which could have been missed during regular viewing without a written transcript.

Statistics

Statistical analysis involved calculating median and interquartile ranges for views, likes and dislikes as the data showed a positive skew. Data analysis was calculated using GraphPad Prism Version 7 (GraphPad Software Inc., La Jolla, CA). Kruskal Wallis tests were used where appropriate. Statistical significance was set at $p=0.05$ *a priori*.

Results

Our search returned 17,000 videos, of which the 50 most viewed videos were assessed. The median number of total views was 5,458 (Q_1 - Q_3 , 3,433-10,327). The number of views ranged from 2,321 to 69,121. Video demographics according to upload source are shown in Table 1. Over half ($n=30$, 60%) of the videos were uploaded by patients, 5 (10%) were uploaded by individual HCPs and 15 (30%) were uploaded by hospitals or professional associations (PA). The median number of views for HCP videos was 11,206 (7,898-50,081) and was significantly higher than patient and PA videos ($p=0.02$). The median number of comments in patient videos was 18.5 (8.75-28), which was higher than HCP and PA videos ($P=0.008$). Patient videos also had a significantly higher number of median likes ($p=0.01$). The median number of dislikes was not significantly different between the three upload sources ($P=0.23$).

Table 2 details the themes of the top 10 comments by upload source. Some videos had comments disabled and some, especially those with the lower view count, had fewer than 10 comments. More than half of the comments analysed (174/333, 52.3%) were irrelevant. Few comments critiqued or praised videos in the comments as this was generally reserved for the like and dislike button. Patient videos had the most requests for further information

in the comments with 28% of the total comments. PA videos had further information requests in 13.3% of comments and HCP videos had this in 25.9% of the total comments.

A total of 19 videos were transcribed before data saturation was achieved, yielding 7 overarching themes and 15 sub-themes. A detailed table summary of how overarching themes of each video were established is provided in Table 3. The main theme of the remaining 31 videos that were not transcribed all fit into one of the 7 categories produced from our thematic analysis.

The overall theme of each video is a useful indicator for the information that is desired to patients to help in their decision for surgery. Life after surgery was the most common theme found in our results, with 17 videos (34%) discussing this subject (Figure 1). Sixteen of these 17 videos were uploaded by patients with previous history of surgery for UC. Thirteen videos (26%) contained information on surgery however 3 (6%) of these were intended as educational tools for HCPs due to detailed surgical information. The remaining 10 (20%) discuss a variety of topics such as removal of cancer risk, surgical timeline and laparoscopic vs open surgery. Six videos (12%) discussed alternative health therapies, 6 videos (12%) showed live footage of a colonoscopy on a patient with UC and four (8%) videos were miscellaneous. Videos were classified as miscellaneous when they had abstract content, such as a music video about UC. The other 3 miscellaneous videos were a woman changing her stoma, a man thanking 'fans' for support and an interview with the CEO of Crohn's and Colitis Canada. Finally, 4 videos (8%) discussed generally what it was like to be a patient with UC such as daily symptoms and medications.

Discussion

This study reports the thematic content of videos on YouTube as it relates to ulcerative colitis and surgery, and how these videos are used. We found that only 30 out of the 50 videos analysed contained information about surgery, 3 of which contained live footage of surgery and were aimed towards education of HCPs. The number of videos with surgical information in the top 50 most viewed videos is low considering the search term specifically included surgery.

In this study 'life after surgery' is prominent in YouTube videos with 34% of the total videos assessed containing this information. The majority of these videos were uploaded by 4 different patients in an attempt to document their 'journey' and received a good response – judged by the number of likes (355) compared to dislikes (107). Videos discussing life after surgery were also found to have a large number of comments from other users requesting further information, particularly regarding the surgery itself. These users were usually thinking of undergoing surgery or were due to have surgery in the weeks after posting the comment.

Worryingly, only five of the videos analysed were uploaded by HCPs. Of these five only one contained information related to surgery. There is a clear desire for YouTube users to seek health information from HCP videos, as evidenced by the significantly higher view count on HCP videos. However, the user demand is not being met due to lack of HCP uploads with desired content. Some PA videos talk to professionals as part of their video; however, the majority of these videos were promotional for private clinics or hospitals.

This data shows that there is an informational need around the long-term burden of surgery. Patient videos with this content stimulated the most discussion in the comments

when compared with videos of a different theme. The most plausible explanation for this in the literature is the desire for patient-patient information sharing. Previous work has highlighted patient desire to seek anecdotal experience through online peer support channels, but there is concern about the quality of information distributed ¹⁵. The clinical accuracy of information in patient uploaded videos and in the comments of patient videos could be a cause for concern, particularly when there is patient to patient advice which could impact patient decisions.

YouTube videos have been noted as useful for medical education, particularly to medical students for clinical examinations of the nervous, cardiovascular and respiratory systems ¹⁶, ¹⁷. This also appears to be the case regarding surgical education. Rapp *et al* found that YouTube is the most used educational source for surgical trainees and faculty ¹⁸. However, the quality of videos for patients appears to be low. YouTube has previously been assessed for IBD related information and it was concluded that the quality of information was low and biased, especially from patient uploaded videos ¹⁹. To add to this, the quality of YouTube videos has been assessed for some surgical procedures including paediatric tonsillectomy and mid-urethral slings, with these studies also concluding information was often misleading ^{20, 21}.

This study has a few limitations. Firstly, the search revealed 17,000 videos however we only analysed the first 50. We deemed this sufficient as after the first 50 videos the view count between videos was minimal and including videos after the 50th could have produced different outcomes not representative of the most viewed content. Previous qualitative assessments of YouTube also use similar sample sizes ^{12, 13}. Secondly, this study used the search term 'ulcerative colitis and surgery' under the assumption these are the keywords a

lay-person would use over more specific types of surgery such as 'restorative proctocolectomy' and 'ileo-anal pouch'. Finally, we did not assess the accuracy of content of the videos where surgical information was given as, based on previous studies, information in videos for patients is likely to be limited and misleading.

This is the first study in the literature to assess the thematic content of YouTube videos discussing surgery for UC. We have outlined the most viewed content for ulcerative colitis and surgery, providing a description of the material that is important to patients. Videos were assessed in a systematic manner with two reviewers to ensure that the data collected was accurate. Coded transcripts were discussed collaboratively with DB, ML and GJ to ensure a consensus.

It is recommended that HCPs engage with YouTube as a source of information and adapt the content of the videos they upload to suit the informational demand illustrated by this study. Life after surgery is a poorly represented topic in HCP and PA videos despite videos of this topic being of most interest to YouTube users. Previous work has highlighted that 90% of patients think that educational material should be prepared according to patient needs ²². Adaptation of content should increase user engagement and will also ensure the distribution of clinically accurate health information online. Finally, it is recommended that there are further studies assessing patient pre-operative informational needs. Establishment of patient informational preferences will help HCPs adapt the content of pre-operative information delivered during consultations and also direct the content of future video uploads.

Conclusion

Patients considering surgery for ulcerative colitis utilise YouTube to acquire information.

There is an informational desire for patients to understand the sequelae of surgery for ulcerative colitis. Trained professionals need to engage in the spread of health information to internet platforms such as YouTube. HCPs should adapt the content of videos they upload to suit user demand. Further studies are required to assess patient pre-operative informational needs to ensure healthcare professionals address patient concerns in clinic.

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